

Autonomy and protection in self-neglect work: the ethical complexity of decision-making

Abstract:

Self-neglect, in which an individual does not attend to their hygiene, health or home surroundings, is one of the most challenging aspects of adult social care practice. In England, its inclusion within the remit of adult safeguarding, as a result of changes in adult social care law introduced under the Care Act 2014, has thrown into relief the ethical dilemmas arising from tensions between respect for autonomy on the one hand and the exercise of a protective duty of care on the other. This paper draws on serious case reviews and safeguarding adult reviews in self-neglect cases, along with findings from adult safeguarding research, to propose that an appropriate balance between these two moral imperatives is not always achieved in self-neglect practice. It considers why autonomy appears to be privileged over other considerations, illustrating the complex interplay between law and ethics that gives autonomy pre-eminence. It then considers how a more nuanced, situated and relational approach to autonomy can enable practitioners to move away from dichotomous interpretations of the moral imperatives present in self-neglect work, and can support more nuanced understandings of the ethics of professional decision-making. Finally it considers the personal and organisational implications of this enhanced ethical literacy.

Keywords:

Self-neglect; autonomy; protection; adult safeguarding; ethical dilemmas; ethical literacy

Introduction

Self-neglect may occur when individuals – wilfully or otherwise – do not attend to their hygiene, health or home surroundings to an extent that poses a danger to their safety or well-being. It takes a range of forms and in England is classified in the Care Act 2014 statutory guidance (DH, 2016) as a form of ‘abuse and neglect’. Self-neglect thus falls within the statutory remit of safeguarding, which places a duty on local authorities to investigate where adults with care and support needs are experiencing (or are at risk of) abuse and neglect and as a result of their needs are unable to protect themselves. Yet the challenges experienced by health and social care professionals when working with people who self-neglect are well documented, both in research and in individual case reviews, which are required by the Care Act when an adult who experiences abuse or neglect dies or sustains serious injury and there is concern about how agencies worked together (Galpin, 2010; Day et al., 2012; Braye et al., 2014; Braye et al., 2015). The question at the heart of the challenge, and which is addressed in this paper, is how services can respect individual autonomy yet at the same time exercise their duty of protection in the context of significant risks and refusal to engage. For these purposes, a working view of the term autonomy is used to denote an individual’s self-determination and personal sovereignty (Ashley, 2012), implying freedom to make one’s own life choices (Harding, 2012; Twomey, 2015). This freedom is codified in the European Convention on Human Rights (ECHR) as the right to liberty (article 5) and the right to private and family life (article 8). Protection is taken to derive from the state’s common law duty of care towards its citizens, encompassing the requirement to protect from foreseeable harm and to promote ECHR rights to life (article 2) and to live free of inhuman and degrading treatment (article 3) (Braye and Brammer, 2012).

Both imperatives are recognised in policy. In England, the statutory guidance accompanying the Care Act 2014 (DH, 2016) embeds empowerment (defined as people being encouraged to make their own decisions, para 4.13) alongside protection as key adult safeguarding principles. While the tension between autonomy and protection is not made explicit, the guidance refers to “the importance of balancing safeguarding with empowerment” (para 14.219). That this is difficult to achieve is evidenced in case reviews. For example, Lawson (2011) has observed that the tension between safety and choice was central to the difficulties experienced by the multi-disciplinary team involved in a case under review, while in another case (LGO and PHSO, 2014), a focus on independence by a caring, well-motivated team led them not to consider whether the individual concerned was able to manage their environment. Determining an individual’s mental capacity to make an autonomous decision, using the framework set out in the Mental Capacity Act 2005, can be pivotal. The Act provides for a decision to be made by others in the best interests of someone who lacks capacity to make it, but supports their right to make an autonomous decision if they have capacity. It is in the latter case that the key difficulty resides. In a survey about self-neglect work of adult safeguarding practitioners and managers working for English local authorities Braye et al., (2014) found that the key challenge most commonly mentioned was working with people considered to have mental capacity and refusing help or support; it is often found too at the centre of individual case reviews. Exploring the resolution of this ethical conundrum, namely how to navigate between principles of autonomy and self-determination on the one hand, and protection or a duty of care on the other, is the focus of this paper.

We draw first on previous research (Braye et al. 2015; Preston-Shoot, 2016) into reviews of individual cases (previously known as serious case reviews (SCRs) and now renamed safeguarding adult reviews (SARs) since implementation of the Care Act 2014. A systematic search of all Safeguarding Adult Boards (SAB) websites in England was undertaken. The analytical method by which themes were derived from these reviews of the outcomes of practice has been described elsewhere (Braye et al. 2015). In the context of this paper the focus is on those reviews that comment on the ethical dilemmas of practice. We add to this evidence from the published research literature to support our contention that the balance between autonomy and protection is not always found in practice with self-neglect, and to illustrate the harms that result. We then explore the question of why autonomy is often found to be privileged, deliberately or unreflectively, over other considerations. Finally, we go on to suggest positive ways forward that might constitute ethical practice in the face of this dilemma and consider the organisational implications of such practice.

Evidence from case reviews

Amongst over sixty individual case reviews that feature self-neglect in England and Scotland (Preston-Shoot, 2016), one-third comment on the complexity of balancing autonomy with protection in cases where an adult who self-neglects is deemed to have decision-making capacity. 50% make recommendations designed to improve mental capacity assessments. 43% refer to skills for trying to engage with people who are hard to reach or who decline assessment and support. 38% emphasise the importance of person-centred practice, namely navigating the complexity of recognising the outcomes desired by the individual but seeking to explore their expressed choices through respectful challenge. Reviews have commonly concluded that adequate consideration was not given to the significance of individuals’ support needs alongside their right to self-determination. For

example, a Scottish review (Glasgow APC, 2015) concluded that the right to self-determination of a mother with dementia and her son had been allowed to override their right to support and protection, such that an incorrect balance had been struck between these competing rights. Similarly, a SAR (Hampshire SAB, 2015) observes that professionals should have questioned whether prioritisation of self-determination was the most beneficial approach to take for a woman with mild learning disability, personality disorder and epilepsy who died following serious but unrecognised health complications. Another (Lambeth SAB, 2012), finding that the professionals had assumed that the individual was making decisions with capacity, concluded that the absence of a plan to meet his housing, care and support needs amounted to a failure of a duty of care.

Many case reviews have also found the question of mental capacity, which is key to the individual's choice about care and support, to be less clear-cut than assumed by those involved. One (Lawson 2011) noted how the presumption of capacity and non-intervention was followed without question, even when the service user was left vulnerable by his decisions. The review concluded that a failure of morale amongst the professionals involved, when faced with disagreements with the service user and his caregiver, led to a failure of will. There was no focus on the person's capacity to take decisions, no carer's assessment, and no systematic consideration of risks and legal options. A SCR focusing on the work undertaken with a young man with Down's syndrome and mental distress concluded that professionals had given 'misplaced respect' (Flynn and Eley, 2015, p33) to his choices. They failed to assess his decision-making capacity when he refused beneficial interventions, despite the strong likelihood that he did not have a clear understanding of the medium to longer-term consequences of doing so. In another (Braye, 2016), concerns were expressed that capacity was treated as an attribute applying to all the individual's decisions rather than to a specific decision as required under section 2 of the Mental Capacity Act 2005, that capacity was not reviewed at all appropriate points, and that medical evidence of possible impaired executive brain function, which would have affected the individual's ability to use and weigh relevant information, was not known to the social care practitioner undertaking a capacity assessment and was therefore not considered.

Several SCRs (Brown, 2014; Klée, 2015) take issue with professionals who justify their approach (often non-intervention) by reference to an individual's lifestyle choice, questioning whether the adults who were self-neglecting in these cases were really weighing up the relevant information necessary to arrive at an informed decision. A SAR (Sunderland SAB, 2015), focusing on self-neglect involving a mother, son and daughter, considered that mental capacity was used by agencies to justify not taking action, but that the outcome was neither empowering nor protective. It observed that lifestyle choice might be a reasonable general statement about the right to self-determination but that it should have been challenged robustly, especially as the decision-making capacity of those involved was doubtful. It concluded that the view that self-determination should take precedence over all other considerations was seriously flawed and that authority to act was not used where clearly it should have been. Unexamined presumptions of capacity often prove to be neither protective nor supportive of individuals' autonomy (Brown, 2014). Scourfield (2010) makes a similar observation when analysing another SCR (Cornwall SAB, 2007). In that case practitioners may have assumed that the adult's self-neglect was the result of a lifestyle choice without clarifying whether she herself consciously saw it as a decision she had made. What these reviews recommend is that practitioners and managers must interrogate what they mean by 'lifestyle choice' and in each unique

case establish the individual's own perceptions and attitudes towards risk, alongside their strengths, resilience and resourcefulness.

Taken together, the case reviews warn of potential dangers: elevating autonomy over consideration and open discussion of potential for harm; taking mental capacity for granted despite indications that it should be assessed; and using terms such as 'lifestyle choice' without an adequate exploration of the extent to which such choices are in fact the clear capacitous wish of the individual. They provide support for more sophisticated and nuanced approach to autonomy that takes into account the intricacies of choice and the complexities of mental capacity.

Evidence from research

Research papers shed further light on the problems raised by the challenge of balancing autonomy with protection in adult safeguarding generally and self-neglect more specifically. Fyson and Kitson (2007; 2010), in studies of practice with people who have learning disabilities, identify how choice/independence and adult safeguarding developed as parallel agendas that have too often failed to connect. Although, since they were writing, the Care Act 2014 and the *Making Safeguarding Personal* initiative (Lawson et al., 2014) have gone some way to providing a framework that can reconcile the two, the legacy of this separation remains and has allowed poor professional practice and abuse to flourish. Fyson and Kitson also argue that a prevailing focus on the development of individuals' practical skills to support their active participation in their communities has not been matched by support in developing the social and emotional skills to live independently, constituting a failure of a duty of care that exposes them to potentially abusive relationships. Accordingly they argue for the position that autonomy must be actively promoted and facilitated, rather than expected to emerge safely by default. Moreover they recommend that, to minimise the possibility of abuse, autonomy must be mediated by effective adult protection measures and that practitioners and managers must review the orthodoxy that promotes independence and choice as the only acceptable goals.

Manthorpe and colleagues (2011) concur that empowerment and protection have been separate discourses, debated on parallel tracks. They argue that, whilst an individual's wishes and needs should form the starting point for a personalised and responsive intervention, safeguarding should also be at the heart of practice. Ash (2010; 2013) too finds that when the tension between protecting autonomy and promoting well-being is resolved in favour of autonomy, there are times when the outcome can be tantamount to abandonment. She suggests that the concept of self-determination has been oversimplified in social work. In her research into safeguarding referrals for older people, she noted an absence of 'proactive work with an older person on understanding potential risks or identifying ways to mitigate these' and that the right to make unwise decisions had become a 'mantra often repeated' (Ash, 2013, p. 108) rather than a starting point for discussion, questioning and reflection. Where this does not take place, professionals may erroneously assume that the individuals they work with invariably share their own starting assumptions about self-determination. Bergeron (2006), reflecting on practice and case file analysis, points out that people in difficult or risky situations may sometimes expect that professionals will provide direction rather than a mutual problem-solving relationship, their own shame and embarrassment at their self-neglect hindering authentic choice. Where professionals' emphasis on autonomy prevents them

from recognising this perception, they then not only disappoint the person's hope of 'rescue' but miss the opportunity to work with them to develop their problem-solving agency.

Braye et al. (2014), researching self-neglect practice, found strong professional commitment to supporting an individual's autonomy to choose their way of life: "The default balance for practitioners overall probably tilted towards autonomy, being prepared to envisage extreme personal deterioration if capacity is present and risks to others are not excessive" (p193). In the study interviews, managers were more oriented towards protection as an expression of the duty of care, possibly as a result of their more overt engagement with organisational responsibilities, but this perspective did not necessarily translate to frontline practice.

Galpin (2010), writing about older people, criticises agencies for not addressing the choices that people are making and argues that protection has become a poor relation to autonomy. She observes that independence and choice as commonly used are 'nebulous concepts' (p254) and that older people are left more vulnerable as a result of a consumerist agenda. Clark (1998) also comments on the conceptual elasticity of empowerment and argues that practice ethics are too general and imprecise to ensure consistent and dependable judgements. He notes social workers' strong attachment to autonomy and self-determination and the negative connotations attributed to paternalism, but suggests that protection may also be beneficial and justified in situations where welfare and safety are compromised by serious risk. Likewise, McDermott (2011), from an ethic of care perspective, argues that principle-based ethical theory falls short of capturing the complexity inherent in decision-making in relation to self-neglect and that uncritical over-emphasis on autonomy, or for that matter protection, equates to lack of care. Care, she argues, is as valuable as autonomy, embodying emotional connection and empathy.

Thus alongside SCRs and SARs, research findings too give cause to question notions of lifestyle choice in relation to self-neglect. Service users' own explanations of their self-neglect often show the impact of demotivation and negative self-perception rather than of conscious choice: "*I got it into my head that I'm unimportant, so it doesn't matter what I look like or what I smell like*"; "*I'm drinking, I'm not washing; I wouldn't say I'm losing the will to live, that's a bit strong, but I don't care, I just don't care*" (Braye et al., 2014, p100). As one practitioner interviewed put it: "*Respecting lifestyle choice isn't the problem; it's where people don't think they're worth anything different, or they don't know what the options are*" (Braye et al. 2013, p45).

The privileging of autonomy

The evidence from reviews and research, which warns against orthodoxy followed unquestioningly, should remind practitioners and managers that favoured ways of practising can become traps that prohibit or confine thoughtful practice (Senge, 1999). Too often, they construct a context that influences how obligations, roles and responsibilities are configured and how subsequent conversations with adults who self-neglect are conducted. In similar vein, both Twomey (2015) and Preston-Shoot (2016) observe that the way practitioners approach encounters with service users may close down an exploration of the interface between autonomous choice-making and providing good care. The observation that autonomy has 'become the 'default' principle of applied principlism, the principle to be appealed to when principles conflict' (Wolpe, 1998, p43), while

originally made in the context of bioethics, seems to be borne out by these reports of contemporary British social care practice. It is important to explore why this should be the case.

There are strong ethical arguments for autonomy; it occupies an important place within principle-based approaches to ethics, and figures in both deontological and consequentialist perspectives (Lillehammer, 2012). Deontologists place emphasis on treating the person as an end, not as a means, a position that implies upholding his or her right to self-determination. Consequentialists are perhaps less wedded to autonomy for its own sake and may in some situations decide against it, yet strong arguments can often be made from a 'rule consequentialism' perspective that the individual is best placed to know what is in their best interests and pursue it in their own way, leading to better outcomes overall. Yet this level of consensus raises the question of whether a principle can become too dominant and too taken for granted. Hale (2009), for example, observes that respect for individual autonomy is an essential part of respect for human dignity, but questions whether respect for human dignity does not also impose a duty on society to protect people from degradation. In essence, the point to emphasise here is that any univocal principle, when taken to extreme, potentially becomes dangerous, here elevating the principle of autonomy to such a level that it swamps considerations of care and support. The converse of course is also possible, namely the urge to protect disregarding a person's self-determination.

Ethics and law can be seen to be in synergy to give autonomy a degree of pre-eminence. Keywood (2003, p358) refers to "the law's recognition of the pre-eminence of autonomy as the appropriate moral foundation for individual agency and responsibility". The statutory presumption of capacity within the Mental Capacity Act 2005 (MCA) - whereby a person must be assumed to have capacity unless it is established (through capacity assessment) that they do not (s.1(2)) - has powerful ethical as well as legal force (Keywood, 2010; Twomey, 2015). When linked with the further statutory principle (section 1(4)) that a person is not to be treated as unable to make a decision merely because they make an unwise decision, it lends considerable support to individual decision-making autonomy. It can render professionals reluctant to question an individual's capacity and choices even when they can identify problematic elements to the individual's decision-making. As Day et al. (2012) identify, if an individual has capacity, practitioners feel they must step back and wait for a crisis. Some research has suggested that the tendency among health professionals is to overestimate capacity rather than to underestimate it (Lepping 2011; Okai et al 2007). The SCRs and SARs that have inquired into cases of adults who self-neglect are also replete with examples of where decisions have not been respectfully questioned and changes in behaviour have not been explored. As Keywood (2010) notes: *"Professionals can and should consider the reasoning abilities of those who benefit from the statutory presumption of capacity. Partly because it does not necessarily respect autonomy to make no inquiry of a person's decision-making abilities but equally significantly, an approach which does not ask questions of a person's presumed competent wishes can result in profound self-neglect"* (p109). Report authors also acknowledge that, while an unthinking approach to the loosely defined concept of autonomy can lead to neglect of risks, an unthinking emphasis on protection clearly runs the risk of imposing paternalistic professional solutions. Yet by the same token, there comes a point where subordinating the well-being and safety of an individual to the ultimate goal of their 'autonomy' may cease to be treating the person as an end in themselves, and result in treating them as a mere means to the end of the principle of that autonomy (Holroyd, 2012).

Further legal support for autonomy derives from the ECHR. The Human Rights Act 1998 incorporated Convention rights into domestic British law and requires all public bodies to give effect to those rights when carrying out their work. Article 8 provides a right to respect for private and family life, and article 5 the right to liberty and security of the person. The former is a qualified right, meaning that the rights of the individual must be balanced with the interests of the community or state, and therefore may be limited where warranted, provided interference in these domains is lawful, necessary and proportionate, and in pursuit of a legitimate aim (such as, in the context of self-neglect, protection of 'health or morals', or of the 'rights and freedoms of others'). The latter is a limited right, permitting breach in particular specified circumstances set out in the Convention, such as lawful detention on mental health grounds, in accordance with a procedure prescribed by law. Nonetheless, they provide important support for arguments that privilege liberty and autonomy, and cautionary benchmarks for the interpretation of rights in practice.

How practitioners understand the legal framework within which they work has a powerful influence on professional judgement. Legal rules that are complicated to understand and apply, including those relating to mental capacity and information-sharing, will shape how practitioners perceive their options in cases (Preston-Shoot, 2016). Lack of legal literacy and a failure to consider all legal options are common themes emerging from SCRs and SARs (Braye et al., 2015). Report authors (for example Lawson, 2011, 2015; Brown, 2014; Glasgow APC, 2015) and researchers (Braye et al., 2014) observe that the MCA is widely misunderstood but is nonetheless used to justify non-intervention. This mirrors the conclusion of the House of Lords Select Committee (2014), a committee of the second chamber of the UK Parliament set up to scrutinise whether the MCA was working as Parliament intended : *"The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult"* (para. 105). The committee concluded that legislation should be drafted in clear and simple terms to ensure that powers and duties are clearly understood and implemented.

The decision-specific nature of capacity assessment under the MCA is arguably difficult to apply in the context of self-neglect, which typically results from the interplay between multiple and often relatively mundane acts or omissions that nonetheless have a damaging cumulative effect. One SCR (Brown, 2014) makes the point that it is often unclear which specific decisions should be the focus of a formal capacity test, and that practitioners lack clarity about when, in an individual's gradual slide into self-neglect, the MCA might provide a mandate to intervene. It argues that the Act itself was formulated with single, well-delineated decisions in mind, and that its focus on cognitive processes fails to address the emotional content of decision-making. Equally it omits explicit consideration of executive capacity, which emerges from the literature (Braye et al., 2011; Hildebrand et al., 2014) as a significant feature in self-neglect. This refers to the cognitive processes - executive functions – that are controlled by the frontal lobes of the brain. Some executive function impairments cause individuals no difficulty in reasoning through a decision in the abstract, as required in capacity assessments, but leave them unable to judge when they should act on that decision, or to process information in the moment when action is called for. In some cases, this might better account for

why self-neglect continues than assuming that it is a result of conscious and deliberate decision-making.

Contemporary political and organisational factors too reinforce the dominance of autonomy, with personalisation a recurrent theme across policy development in adult social care, and choice and control given reinforcement by the statutory assumption (section 1(3)(a), Care Act 2014) that an individual is best placed to judge their own wellbeing. In reflecting on when interference with choice is justified, practitioners and managers may find little support in a neo-liberal public policy and societal context where the emphasis is on minimal government and on autonomy and individual choice (Galpin, 2010). As SCRs (Preston-Shoot, 2016) and researchers (Day et al., 2012) have observed, behaviours such as alcohol abuse may be construed either as a way of life or as evidence of ill-health; the view taken will shape the options that practitioners perceive are available to them to intervene. When agencies are under severe financial pressures, practitioners and managers may divert resources to those who express a willingness to change and away from those believed to be making a lifestyle choice (Cornwall SAB, 2007; Torbay SAB, 2011). In a related vein, Ash (2013) raises the possibility that the emphasis on individual choice might in practice be both a way of unconsciously managing dissonance arising from adult safeguarding policy and a device to navigate through high caseloads and resource shortages, by shifting responsibility from services and from the practitioner. Such dynamics are arguably enhanced in self-neglect, where the combination of a service user reluctant to engage and a system overloaded with demands can result in the practitioner taking the service user's initial 'no' for a definitive answer and walking away (Braye et al., 2014).

Brown (2014) offers a trenchant critique of the uncritical prioritisation of autonomy, which in one case resulted in professionals relying on an unfounded notion that the person was making free and informed choices when in fact his ability to manage his environment was severely compromised. She warns of the danger of collectively prioritising an illusion of autonomy over pragmatic humane intervention to secure an individual's wellbeing, dignity and right to life. Faced with such ethical and legal complexities, practitioners fall back on service user choice and self-determination as a means of managing dissonance arising from ambiguities in public policy and law (Day et al., 2012; Ash, 2010; 2013) with the result that some people are essentially abandoned (Fyson and Kitson, 2010).

Towards ethically literate practice

Uncritical adherence to ethical principles can give rise to unsophisticated approaches to practice; it is simplistic to assume that autonomy is good and paternalism is bad, just as it is to assume the opposite. Preston-Shoot's (2001) review of literature points to how self-determination is problematic as a sole guiding principle for practice. For instance, it assumes that choice is empowering without recognising that decision-making may be profoundly influenced by powerful emotions, such as fear, hopelessness, self-hatred, pride in one's own independence, or the desire to be accepted. Treating the kinds of decisions that are made in self-neglect work as a dispassionate selection between courses of action does little justice to the feelings or experiences that may be at work and that may affect the person's views.

More nuanced and less dichotomous interpretations of the moral imperatives for autonomy and protection are needed. Drawing on the evidence explored earlier in this paper, there will be situations in which respect for autonomy must entail questioning how far apparent choice in self-neglectful circumstances is truly chosen, and respectful curiosity (or even challenge) from the practitioner about the thoughts and feelings underlying the individual's apparent decisions. Equally, protection does not mean denial of an individual's views, wishes and feelings, or the total removal of all risks to their safety and wellbeing. And where grounds exist for intervention to be imposed upon an individual, notwithstanding their mental capacity – use of mental health, environmental health or housing legislation are examples here – self-determination may be compromised in the short term in order to preserve the ability to exercise autonomy in the longer-term. As Keinemans and Kanne (2013) identify, moral issues involve a certain level of nuance: “the options available are, as it were, fluid, and it is possible to distinguish between two opposing extremes, but there is an infinite number of nuances in between” (p392).

Practitioners are called upon to move away from the technical-rational logic of ‘solving the problem’ of self-neglect and take a more situated, relational approach to deciding upon the right course of action. More subtle understandings of what autonomy itself involves, taking account of the circumstances, outlook and meaning of autonomy for the individual (McDermott, 2011), can help to point the way to effective and ethical approaches. One such understanding potentially comes from the argument that the (neo)liberal emphasis on independent self-determination is misguided. Rather than consisting simply of non-interference with independent actions by isolated and self-reliant individuals, autonomy in real terms can be seen as existing within relationships that may give direction, support and meaning to one's decisions. Thus real, meaningful autonomy is relational rather than individualistic (Nedelsky, 1989). Though as a feminist Nedelsky recognises the potential for restrictions that relationships may involve, she recognises how valuable they can be also.

There are at least two implications for practitioners here. One is explicit recognition of the relational context in which an individual is situated (Clough, 2014; Harding, 2012), which, given the complex influences on self-neglect, can include past relationships and life experience. Indeed, sometimes individuals respond more readily to realisation of the impact that their self-neglect is having on others than to the impact that it has on them (Braye et al., 2014). Another is that engaging in dialogue with clients on making decisions need not be seen as impinging on their autonomy, but as supporting it (Widdershoven and Abma, 2012) - engaging in practice that privileges relationship-building and negotiation, aiming always to preserve the individual's sense of control. Clark (1998) advises that practitioners should stay alongside clients when decisions are still in the balance and that legal coercion should be avoided where possible, guidance that accords with the evidence-base for positive outcomes in self-neglect (Braye et al., 2014). When working with people who self-neglect, it is important to recognise that past experiences, social isolation, or a sense of helplessness and fear may mean that individuals do not see a problem in their circumstances or are unable or unwilling to address them (Day et al., 2013; Braye et al., 2014). Thus, careful assessment is needed of all the factors that limit coping and self-care, including of executive and functional impairment, seeking a means of maximising an individual's safety while honouring their goals (Hildebrand et al., 2014). As Bergeron (2006) notes, a unique intervention informed by the history of how a person has lived and their own perspective on risk and safety, does not lose the foundations of their lifestyle choices but expresses healthier versions of them.

Thus 'concerned curiosity' (Braye et al., 2014) is key to deeper exploration of what autonomy means in any given situation. The statutory presumption of capacity may safeguard liberty but may not promote an individual's autonomy if their decision-making process is not subject to scrutiny, and practitioners should discover what service users value concerning autonomy (Keywood, 2010). Twomey (2015) in similar vein stresses the importance of relationships being taken into an ethical space in which people work together to make sense of what is happening and to find a way forward that will enable the exercise of meaningful autonomy, and Scourfield (2010) suggests that practitioners should talk with people about the outcomes they want to achieve rather than just accept service refusal. Ash (2013) advises discussion of the choices people are making and the risks inherent in their decisions. Her observation that this is not currently a strong feature of practice raises concern about potential violation of the Mental Capacity Act; if the risks inherent in an individual's situation have not been raised with them, the practitioner has no way of knowing that the individual has explicitly considered all the information that has a bearing on their decision, which under section 3, MCA 2005, they must be able to understand, retain, use and weigh. It is unclear from SCRs and SARs, which reach similar conclusions about the extent to which risks are explored, whether this omission is because professionals lack confidence in assertive questioning or feel prohibited from challenging people's apparent choices. Either way, a more comprehensive approach to dialogue is in keeping with a broad view of what may be termed 'positive autonomy' (McDermott, 2011). As distinct from negative autonomy, which focuses on guaranteeing people's rights to decide without interference, positive autonomy promotes positive growth that actively helps people to enhance their freedom within their own lives, perhaps close to what Hildebrand et al. (2014) call maximising people's capacity to self-nurture. Flynn (2007) recommends that a life-transforming choice such as refusal of care and support by an individual known to be vulnerable should result in assessment of decision-making capacity and consideration of the factors that prompted the decision, before choice is used as a rationale for setting aside a duty of care. Preston-Shoot (2001) advises that practitioners should maintain contact, explore people's fears and options, and work with individuals to gain acceptance for less risky decisions, remaining alert to situations where decisions are taken in a context of intimidation and undue influence.

In addition to more nuanced interpretations of autonomy, more nuanced understandings of the ethics of professional decision-making are also needed. Clark (2012) argues that the process of practical reasoning in ethical decisions is inadequately conceptualised: broad principles in ethical codes are valuable but don't provide answers in the localised context of specific cases; nor does the linear logic of decision-making models reflect the realities of practice. He constructs ethical decision-making as a hermeneutic process illuminated by three principles: recognition of the role of personal biography, culture and lived experience; engagement in an iterative process in which all understanding is tentative and provisional; and the importance of mutual dialogue. Counselling against early closure of a decision, he recognises that "professionals meantime have to live creatively with the discomfort of no immediately available solution, as well as the discomfort that the time available to find a solution is often strictly limited" (p131).

Banks (2016) proposes the notion of 'ethics work', differentiated from textbook ethics by its focus on social workers as moral agents in the context of how they make sense of situations encountered, work out the right course of action, and justify who they are and what they do. Her

conceptualisation of the 'work' of ethics work - embedded and embodied in the emotions and relationships of everyday practice – resonates strongly with research findings on the components of effective practice in self-neglect (Braye et al., 2014).

The focus on relationship, so appropriate in self-neglect work, is pursued too by Weinberg and Campbell (2014), seeing an ethical relationship not as a product but as a process that “instead of being impersonal and abstract is highly personal and specific, involving affect, not just cognition” (p43). Weinberg (2010) brings too an additional dimension to the construction of social work ethics, arguing that a view of practitioners as autonomous agents, enacting universal abstract principles, constrains understanding of the wider structural influences and paradoxes within which practice is located, and the taken-for-granted discourses that frame their development. Thus the notion of ethical dilemma is, she argues (Weinberg, 2014), better replaced by that of ideological dilemma, which (citing Billig et al., 1988) she construes as emanating from the contradictory principles and practices that emerge as discourses in the society or culture as a whole. Such a perspective provides an important recognition that ethical decision-making in self-neglect work is inevitably affected by societal expectations that themselves are complex. For example, Lauder et al. (2005) note two cultural factors - preoccupation with hygiene and sanitation, and tolerance of eccentricity - which together produce an “ambivalent and contradictory attitude to those who self-neglect” (p47).

These approaches invite a broader construction of what constitutes ethical practice, a strengthened ethical literacy, which resonates strongly with evidence on the importance of time and relationship in self-neglect work (Braye et al., 2014) and with the evidence emerging from SCRs and SARs on failures to engage with the complexity of autonomy in self-neglect.

The personal and organisational implications of ethically literate practice in self-neglect

SCRs and SARs signpost ethically literate practice, even if it is often identified by what did not happen in the cases reviewed. Thus, the relationship that practitioners have with service users should be characterised by concerned curiosity demonstrated through authoritative but respectful questioning. This will explore any rejection of services and the reasoning behind the person's decisions. But the relationships upon which ethically literate practice in self-neglect depend have implications for the practitioners involved, and for the organisational context in which they work. Practitioners' narratives (Braye et al., 2014) demonstrate that self-neglect work is personally demanding, engaging personal sensibilities and occasionally breaching personal boundaries: *“You have to give a lot of yourself I think to win the trust of somebody who's not engaging with any other services”*; *“I think it's very emotive as well and you're entering ... into someone's personal life and their world, they don't want you to go, so it can be a really uncomfortable place”* (p135). Some reported helplessness, anxiety, stress, self-questioning and a sometimes intolerable sense of responsibility. Their organisational context posed challenges too, with its expectations of time-limited care-management style approaches, and a norm of case closure in the face of service refusal. Persistent advocacy with managers was often needed to secure the time to engage in the slow-burn work that could result in relationships of trust with service users.

At times practitioners are less exercised by the ethical dilemmas inherent in a specific case than by the frustrations of an organisational environment that denies them the time and space to work in

the way they think appropriate. The concept of moral distress is pertinent here. This is differentiated from the notion of ethical dilemma, which is construed as a choice between two courses of action, each of which would compromise an ethical principle (Banks, 2012). Moral distress arises “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Jameton, 1984, p6). The practitioner knows what is morally appropriate but is prevented from implementing it (Lynch and Forde, 2016; Mänttari-van der Kuip, 2016). As Weinberg (2009) notes, the concept is valuable “in tying the personal with the political by recognizing the institutional barriers that hamper practitioners from functioning in ways they would deem ethical as well as the emotional fall-out from those difficulties” (p2), although she cautions that the paradoxical nature of social work, and the likelihood that ethical trespass may ensue regardless of what decision is made, mean that no single response is likely to be entirely morally right.

But organisational adjustments are clearly needed if practitioners are to be able to take the more nuanced ethical approaches suggested and to engage in processes of moral reasoning that can encompass the complexities of situation and relationship. Two features of organisational life emerge from research evidence (Braye et al., 2014) as influential on how practitioners are able to work effectively with self-neglect. First are forums for exploration and dialogue about the ethical dilemmas involved in decision-making. Supervision has a key role to play here, both in questioning and promoting the development of ethical positioning, and in supporting the practitioner with the affective component of their work. Practitioners draw benefit too from opportunities to come together in practice development discussion and/or to engage with a multiagency network for exploration of the different ethical perspectives likely to be held on any given case. As Weinberg and Campbell (2014) note, to secure meaningful engagement in ethical relationships “requires social workers to engage actively in a critically reflective process, to be vulnerable, to explore instances of ethical trespass, to grapple with contradictions, and to share their insecurities and confusions” (p47).

The second significant organisational feature is workflow: the expectations the organisation has on how cases will routinely progress through predictable stages. The research found examples of how local authorities had adjusted both team roles and case-processing timescales to create opportunities for some staff to work in a more time-intensive way over a longer period of time with some service users, and to engage in the necessary, unfolding ‘ethics work’ (Banks, 2016). Such adjustments can free practitioners to do what has frequently been referred to as ‘real social work’ (Braye et al., 2014, p. 180). Thus recognition of the organisational implications of ethically literate practice in self-neglect will better support practitioners with the ethical dilemmas inherent in the work and mitigate the potential ‘moral distress’ of being unable to implement the outcomes of more nuanced ethical perspectives.

Conclusion

Focusing attention on SCRs and SARs of course has implications for the kind of evidence that informs this discussion of moral reasoning in self-neglect. Such reviews are carried out in ‘worst case scenarios’ where fatalities have occurred or narrowly been avoided. It is therefore to be expected that their findings generally show inadequate attention paid to protection rather than to autonomy. It must be acknowledged that harms of a different nature may result from an elevation of protection

above autonomy. But the consistent messages emerging from reviews and research have much to tell us about the potential adverse consequences of simplifying or idolising autonomy, and the reasons why practitioners may nevertheless find themselves doing so. What these messages convey is the need for a sophisticated and reflective approach to understanding, weighing up, and communicating judgements about autonomy and protection and what they mean in any given situation of self-neglect, and an approach to ethical decision-making that does justice to the complexity of the lived experience of both service users and practitioners.

References

Ash, A. 2010. 'Ethics and the street-level bureaucrat: implementing policy to protect elders from abuse.' *Ethics and Social Welfare*, 4(2): 201-209.

Ash, A. 2013. 'A cognitive mask? Camouflaging dilemmas in street-level policy implementation to safeguard older people from abuse.' *British Journal of Social Work*, 43(1): 99-115.

Ashley, V. 2012. *Philosophical Models of Personal Autonomy*. Essex: Essex Autonomy Project.

Banks, S. 2012. *Ethics and Values in Social Work*. 4th ed. Basingstoke: Palgrave.

Banks, S. 2016. 'Everyday ethics in professional life: social work as ethics work.' *Ethics and Social Welfare*, 10(1): 35-52.

Bergeron, L.R. 2006. 'Self-determination and elder abuse: do we know enough?' *Journal of Gerontological Social Work*, 46(3): 81-102.

Braye, S. 2016. *Safeguarding Adults Review of the Circumstances Concerning Mr BC*. London: City & Hackney Safeguarding Adults Board.

Braye, S. and Brammer, A. 2012. 'Law on personalisation' in *Social Work with Adults*, edited by M. Davies. Basingstoke: Palgrave.

Braye, S., Orr, D. and Preston-Shoot, M. 2011. 'Conceptualising and responding to self-neglect: challenges for adult safeguarding.' *Journal of Adult Protection*, 13(4): 182-193.

Braye, S., Orr, D. and Preston-Shoot, M. 2013. *A scoping study of workforce development for self-neglect work*. Leeds: Skills for Care.

Braye, S., Orr, D. and Preston-Shoot, M. 2014. *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: Social Care Institute for Excellence.

Braye, S., Orr, D. and Preston-Shoot, M. 2015. 'Serious case review findings on the challenges of self-neglect: indicators for good practice', *Journal of Adult Protection*, 17(2): 75-87.

Brown, H. 2014. *Serious Case Review WD*. Waltham Forest Safeguarding Adults Board (Unpublished).

- Clark, C. 1998. 'Self-determination and paternalism in community care: practice and prospects.' *British Journal of Social Work*, 28: 387-402.
- Clark, C. 2012. 'From Rules to Encounters: Ethical Decision-making as a Hermeneutic Process.' *British Journal of Social Work* 12(2): 115–135.
- Clough, B. 2014. 'What about us? A case for legal recognition of interdependence in informal care relationships.' *Journal of Social Welfare and Family Law*, 36(2): 129–148.
- Cornwall SAB. 2014. *Learning Together Serious Case Review. The Reassurance of Disengagement*. Cornwall and Isles of Scilly Safeguarding Adults Board
- Day, M.R., Leahy-Warren, P. & McCarthy, G. 2013. 'Perceptions and views of self-neglect: a client-centred perspective.', *Journal of Elder Abuse & Neglect*, 25(1): 76-94.
- Day, M.R., McCarthy, G. & Leahy-Warren, P. 2012. 'Professional social workers' views on self-neglect: an exploratory study.' *British Journal of Social Work*, 42(4): 725-743.
- DH. 2016. *Care and Support Statutory Guidance*. London: Department of Health.
- Flynn, M. 2007. *The Murder of Steven Hoskin. A Serious Case Review. Executive Summary*. Truro: Cornwall Adult Protection Committee.
- Flynn, M. and Eley, R. 2015. *A Serious Case Review, James*. Suffolk Safeguarding Adults Board.
- Fyson, R. and Kitson, D. 2007. 'Independence or protection – does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall.' *Critical Social Policy*, 27(3): 426-436.
- Fyson, R. and Kitson, D. 2010. 'Human rights and social wrongs: safeguarding adults with learning disabilities.' *Practice*, 22(5): 309-320.
- Galpin, D. 2010. 'Policy and the protection of older people from abuse.' *Journal of Social Welfare and Family Law*, 32(3): 247-255.
- Glasgow APC. 2015. *Significant Case Review, Mrs Ellen Ash*. Glasgow Adult Protection Committee.
- Hale, B. 2009. 'Dignity.' *Journal of Social Welfare and Family Law*, 31(2): 101-108.
- Hampshire SAB. 2015. *Safeguarding Adult Review Concerning Ms B*. Hampshire Safeguarding Adults Board.
- Harding, R. 2012. 'Legal constructions of dementia: discourses of autonomy at the margins of capacity.' *Journal of Social Welfare & Family Law*, 34(4): 425–442.

Hildebrand, C., Taylor, M. and Bradway, C. 2014. 'Elder self-neglect: the failure of coping because of cognitive and functional impairments.' *Journal of the American Association of Nurse Practitioners*, 26: 452-462.

Holroyd, J. 2012. 'Clarifying capacity: value and reasons' in L. Radoilska (ed) *Autonomy and Mental Disorder*, Oxford University Press, Oxford, pp145-169

House of Lords Select Committee. 2014. *Mental Capacity Act 2005: Post-Legislative Scrutiny*. London: The Stationery Office.

Jameton, A. 1984. *Nursing Practice: The Ethical Issues*. London: Prentice-Hall.

Keinemans, S. & Kanne, M. 2013. 'The practice of moral action: a balancing act for social workers.' *Ethics and Social Welfare*, 7(4): 379-398.

Keywood, K. 2003. 'Gatekeepers, proxies, advocates? The evolving role of carers under mental health and mental incapacity law reforms.' *Journal of Social Welfare and Family Law*, 25(4): 355–368.

Keywood, K. 2010. 'Vulnerable adults, mental capacity and social care refusal.' *Medical Law Review*, 18(1): 103-110.

Klée, D. 2015. *Safeguarding Adult Review in respect of Mr AA*. Norfolk Safeguarding Adults Board and Suffolk Safeguarding Adults Board.

Lambeth SAB. 2012. *Serious Case Review, Mr A*. Lambeth Safeguarding Adults Board

Lauder W., Davidson, G., Anderson, I. and Barclay, A. 2005. 'Self-neglect: the role of judgements and applied ethics.' *Nursing Standard*, 19(18): 45–51.

Lawson, J. 2011. *A Serious Case Review in Respect of Mr BB*, London: Westminster Safeguarding Adults Board, London Borough of Westminster.

Lawson, J. 2015. *Serious Case Review in Respect of ZZ*. London: Camden Safeguarding Adults Partnership Board.

Lawson, J., Lewis, S. and Williams, C. 2014. *Making Safeguarding Personal: Guide*. London: Local Government Association and Association of Directors of Adult Social Services.

Lepping, P. 2011. 'Overestimating patients' capacity.' *British Journal of Psychiatry*, 99(5): 355-356.

LGO and PHSO. 2014. *Investigation into a Complaint against South Essex Partnership University Trust and Bedford Borough Council*. Reference number JW 111510 and 11010604. Coventry and London: Local Government Ombudsman and Parliamentary and Health Service Ombudsman.

Lillehammer, H. 2012. 'Autonomy, value, and the first person' in *Autonomy and Mental Disorder*, edited by L. Radoilska, 192-213, Oxford: Oxford University Press.

Lynch, D. & Forde, C. 2016. 'Moral distress' and the beginning practitioner: preparing social work students for ethical and moral challenges in contemporary contexts.' *Ethics and Social Welfare*, 10:2: 94-107.

Mänttari-van der Kuip, M. 2016. 'Moral distress among social workers: the role of insufficient resources.' *International Journal of Social Welfare*, 25: 86-97.

Manthorpe, J., Stevens, M., Rapaport, J., Challis, D., Jacobs, S., Netten, A., Jones, K., Knapp, M., Wilberforce, M. and Glendinning, C. 2011. 'Individual budgets and adult safeguarding: parallel or converging tracks? Further findings from the evaluation of the Individual Budget pilots.' *Journal of Social Work*, 11(4): 422-438.

McDermott, S. 2011. 'Ethical decision-making in situations of self-neglect and squalor among older people.' *Ethics and Social Welfare*, 5(1): 52-71.

Nedelsky, J. 1989. 'Reconceiving autonomy: sources, thoughts and possibilities.' *Yale Journal of Law and Feminism*, 1(1): 7-36.

Okai, D., Owen, G., McGuire, H., Churchill, R. and Hotopf, M. 2007. 'Mental capacity in psychiatric patients.' *British Journal of Psychiatry*, 191(4): 291-297.

Preston-Shoot, M. 2001. 'Evaluating self-determination: an adult protection case study.' *Journal of Adult Protection*, 3(1): 4-14.

Preston-Shoot, M. 2016. 'Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work.' *Journal of Adult Protection*, 18(3): 131-148.

Scourfield, P. 2010. 'Reflections on the serious case review of a female adult (JK).' *Journal of Adult Protection*, 12(4): 16-30.

Senge, P. 1990. *The Fifth Discipline: The Art and Practice of the Learning Organization*. London: Century Business.

Stolee, P., Hillier, L., Harris, D., Hamilton, P., Kessler, L., Madsen, V. and Le Clair, J. 2009. 'Sustained transfer of knowledge to practice in long-term care: facilitators and barriers of a mental health learning initiative.' *Gerontology & Geriatrics Education*, 30(1): 1-20.

Sunderland SAB. 2015. *Safeguarding Adults Review Concerning Angela, Barry and Claire. Final Executive Summary*. Sunderland Safeguarding Adults Board.

Torbay SAB. 2011. *Serious Case Review Executive Summary, Ms Y*. Torbay Safeguarding Adults Board.

Twomey, M. 2015. 'Why worry about autonomy?' *Ethics and Social Welfare*, 9(3): 255-268.

Weinberg, M. 2009. 'Moral distress: a missing but relevant concept for ethics in social work.' *Canadian Social Work Review*, 26(2): 139-151.

Weinberg, M. 2010. 'The social construction of social work ethics: politicizing and broadening the lens.' *Journal of Progressive Human Services*, 21(1): 32-44.

Weinberg, M. 2014. The ideological dilemma of subordination of self versus self-care: Identity construction of the 'ethical social worker.' *Discourse & Society*, 25(1): 84 –99.

Weinberg, M. and Campbell, C. 2014. 'From codes to contextual collaborations: shifting the thinking about ethics in social work.' *Journal of Progressive Human Services*, 25: 37–49.

Widdershoven, G. & Abma, T. 2012. 'Autonomy, dialogue, and practical rationality' in *Autonomy and Mental Disorder*, edited by L. Radoilska, 217-232. Oxford: Oxford University Press.

Wolpe, P.R. 1998. 'The triumph of autonomy in American Bioethics: a sociological view' in *Bioethics and Society: Constructing the Ethical Enterprise*, edited by R. DeVries & J. Subedi, 38-59. New Jersey: Prentice Hall.